

# 2020 SKIN CANCER VISIONS



The Melanoma  
Taskforce

# CONTENTS

## **3. Introduction**

- Pauline Latham OBE MP
  - About the MTF
- 

## **5. Executive Summary & Priorities for Action**

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## **8. The Changing Skin Cancer Landscape**

- Implementing the 2015 Visions
- 

## **9. Skin Cancer in 2015**

- Where are we now?
- 

## **22. 2020 Skin Cancer Visions**

- A manifesto for change
- 

## **26. Conclusions**

---

## **27. Appendix**

- Working Group Members
-



# INTRODUCTION

## – PAULINE LATHAM OBE MP



**The Melanoma Taskforce has been meeting since 2010 to discuss how to improve the lives of patients with melanoma and other forms of skin cancer. Our first publication was the 2015 Skin Cancer Visions, a report which set out our aims and objectives for improving the situation in skin cancer by the General Election this year. The majority of those visions were taken on board by the Department of Health when it produced its own Visions report in early 2011.**

This was a positive step and there have been many improvements for skin cancer patients since 2010. Three new treatments for advanced melanoma have been approved by NICE, under-18s have been banned from using sunbeds and the first Be Clear on Cancer campaign for skin cancer has been piloted in the South West of England. But the Taskforce does not want to rest on its laurels. Melanoma incidence continues to rise and there are concerns that services will become increasingly fragmented without national leadership. A lack of specialist staff, particularly nurses and dermatologists, remains a concern.

With this in mind, I am delighted to be able to present the 2020 Skin Cancer Visions, our new manifesto for change. There is much to do between now and 2020 to make sure the objectives we've set out can be met but I believe our aims are achievable. As the new Chair of the Taskforce, I am grateful to Siân James, the former MP for Swansea East, for all her work over the last five years in establishing the group and leaving us with such a strong base to help improve patient care in the future. With a new Parliament ahead of us, I strongly urge our colleagues in the NHS, the Government and the wider stakeholder community to take action to make these Visions a reality over the next five years.



**Pauline Latham OBE MP**



# INTRODUCTION – ABOUT THE MELANOMA TASKFORCE

**The Melanoma Taskforce is chaired by Pauline Latham OBE MP and brings together experts from across the skin cancer pathway to make positive recommendations for how to improve outcomes for melanoma and other skin cancers. The Taskforce has been busy since it was founded in 2010, publishing a number of well-received reports as well as meeting with Ministers and senior NHS figures to call for improvements in patient care.**

The Taskforce published the 2015 Skin Cancer Visions in 2010. The Visions were more than 20 recommendations for improved skin cancer care, many of which were adopted by the Department of Health a year later. Since that point, the Taskforce has focused on finding ways to implement these proposals within the NHS. The Quality in Melanoma Care: A Best Practice Pathway and the Commissioning Toolkit gave commissioners expert advice on how to implement high quality care for melanoma, the most advanced form of skin cancer. The Commissioning Toolkit was endorsed by NHS Clinical Commissioners, the independent collective voice of clinical commissioning groups (CCGs), in the hope that these examples of best practice would be adopted by care providers across the country. But as with many cancers, the best cure is preventing the cancer developing in the first place. The Taskforce

has also worked with its members and partners from across the skin cancer landscape to support efforts to raise awareness and encourage early diagnosis. In 2011, the Taskforce developed Mole and Skin Check Guidelines in association with the British Association of Dermatologists and the Hair & Beauty Industry Authority, recognising the important role that health and beauty professionals can play in identifying suspicious moles and other changes in people's skin.

The membership of the Taskforce includes representatives from patient groups, professional bodies and leading experts from across the NHS. Working with the support of Parliamentarians, the Taskforce is looking to continue to make a positive difference to the lives of skin cancer patients across the UK for many years to come.



## PRIORITIES FOR ACTION

**Skin cancer incidence is rising and is likely to continue to rise for years to come. The NHS can, and must, do all it can to design the best services and improve patient care to stop mortality increasing at the same time. The 2020 Visions may be aspirations for skin cancer services over the next five years, but there are steps the NHS can take now that will make a significant impact on patients' lives. These Priorities for Action would see drastic improvements in skin cancer prevention, make more care available from specialist staff and ensure that the quality of services are monitored and maintained.**

There have been a number of reasons for the skin cancer community to celebrate since the publication of the first Visions report in 2010. The NICE approval of the first new treatments for advanced melanoma patients in more than 30 years has offered new hope for patients with the most severe cases of the condition. The acknowledgment of the importance of strong messages around sun safety and the prevention of skin cancer has led to significant changes such as the legislation around sun beds in England, Wales and Northern Ireland and the development of the first Be Clear on Cancer pilot scheme for melanoma over the summer of 2014. There are also encouraging signs that Hospital Trusts across the country

have adopted a multi-disciplinary approach for skin cancer that brings specialist care for patients together in one place. Nevertheless, there remain serious concerns about waiting lists for dermatology and skin cancer services and there are reports of significant shortages in the number of staff in the skin cancer workforce.

Despite this, there are still a number of areas of concern that must be addressed as a matter of priority. This report sets out detailed Visions that show the level of ambition that it is possible to achieve over the coming five years. These priorities for action detail the steps that could be taken by NHS England and others immediately to make a significant impact on skin cancer care.





## 1. PREVENTION AND EARLY DIAGNOSIS

In the long term, prevention and early diagnosis measures will be essential to halting the rise in skin cancer incidence and sun safety is crucial to this. Patient groups, GPs and others are doing admirable work across England to make their patients and the public aware of the risk factors for skin cancer and to encourage them to adopt safe practices. But these groups cannot hope to make the required impact alone. The Taskforce would like the Department of Health, Public Health England and NHS England to commit to analysing the data from the skin cancer Be Clear on Cancer pilot as soon as possible and roll the campaign out nationally if it has been successful at boosting rates of early diagnosis. There must also be a national awareness campaign that focuses on prevention as well as early diagnosis to address the rise in skin cancer incidence. Furthermore, the commissioners of public health campaigns should commit to funding for these skin cancer campaigns for at least the next five years in order to ensure it has the time and support to make a long term impact on the behaviour of the public.

## 2. PROVIDING SPECIALIST CARE

Multi-disciplinary teams (MDTs) are widely acknowledged as being essential in providing high quality cancer care. Appropriately trained specialist nurses are one of the most important parts of any MDT and we are concerned that there are not enough skin cancer or dermatology specialist nurses either currently at work or entering the specialism. The Taskforce calls on NHS England to adequately incentivise nurses to specialise in these areas. In addition, NHS England and medical schools must work together to increase the amount of training available to student doctors and nurses in both dermatology and skin cancer and to look into ways of increasing the amount of continuous professional development (CPD) accredited training schemes available in these areas. This may require more funding from the NHS but it would be a worthwhile investment in the lives of patients. The NHS must also adequately ensure enough specialist staff are in place to handle any increased workload following a national awareness campaign.



### 3. ADEQUATE ASSESSMENT OF SKIN CANCER SERVICES

It is also crucial that any improvements made in skin cancer care can be adequately measured and examples of best practice are shared throughout the NHS. At the same time, measurement of the quality of services can identify areas where Trusts are underperforming and ensure appropriate action is taken to stop patient care suffering. Appropriate monitoring also offers an incentive to commissioners to maintain funding for improvements in services. The best way of measuring the successes of cancer services is NHS Peer Review, which currently faces an uncertain future. NHS England must acknowledge the importance of this service and take steps to secure its future. The Taskforce would particularly like to see funding allocated to maintain the service at current levels and for NHS England to guarantee that peer review for skin cancer will be maintained. Appropriate benchmarking at a national level will also assist with monitoring the progress made against the Skin Cancer Visions set out in this document.

### 2020 SKIN CANCER VISIONS – METHODOLOGY

The 2020 Skin Cancer Visions were developed as a collaborative effort between Taskforce members and are based on an assessment of the current challenges in melanoma and the progress made since the original 2015 Visions were published. The Taskforce distributed a questionnaire to all its members, asking for feedback on the current challenges in melanoma, where progress has been made since 2010 and where problems remain unsolved. Members were also asked what improvements in care might be possible by 2020. The Chair of the Taskforce, Siân James MP, then convened a working group of experts to discuss the findings in detail and to develop a new set of aspirations for the years ahead. This working group included experts from across the pathway, and was made up of representatives of patient and professional groups, Public Health England and clinical specialists from primary care, dermatology and oncology. A full list of working group members can be found in the appendix.

It is hoped that this report will be used to influence Ministers, the NHS and other policy makers to improve the quality of skin cancer services across the country. In particular, it will form the basis of the Taskforce's input into the Skin Cancer Strategy, the development of which is being led by Harpal Kumar of Cancer Research UK.





## THE CHANGING SKIN CANCER LANDSCAPE – IMPLEMENTING THE 2015 VISIONS

**The Taskforce published the 2015 Skin Cancer Visions in 2010, its vision for the way services for this cancer should have looked five years later. 17 of these recommendations were adopted by the Government in its own skin cancer strategy later that year. Since then, we have seen a number of developments, from new awareness and early diagnosis campaigns through to the emergence of several new treatments for patients with advanced melanoma.**

Before looking ahead to 2020, the Taskforce examined this initial set of visions to see how much progress has been made. Considerable concern was expressed about the lack of progress made in many of the areas covered by the original Visions. In particular, it was felt that primary care clinicians, with the support of better training, could be better utilised in skin cancer care and that uncertainty around NHS Peer Review and the level of specialist staff could significantly impact the quality of care for patients. The Taskforce also welcomed a number of positive developments such as the increasing availability of treatments for advanced melanoma, three of which have been NICE approved since the first Visions report.

There are many potential explanations for this lack of progress. Cancer services have undergone a major reorganisation since the Taskforce was established. This has led to uncertainties over the future of some services and the availability of funding for others. The reorganisation also led to a change in leadership in cancer, with strategies like the Department of Health's skin cancer visions being subsumed into NHS England's cancer strategies and control over services being devolved to Clinical Commissioning Groups and other bodies. The new set of Visions must take this evolving landscape into account and ask who is now responsible for improving services for skin cancer patients.





# SKIN CANCER IN 2015 – WHERE ARE WE NOW?



**Taken together, skin cancers (including non-melanoma skin cancers) are the most common type of cancer in the UK. In 2011, there were 13,348 cases of malignant melanoma in the UK. Melanoma alone is the fifth most common type of cancer in the UK. Malignant melanoma is also the 18th most common cause of cancer death in the UK, causing 1% of all deaths from cancer. In 2012, this meant that 2,148 people died from melanoma.**

Melanoma affects a disproportionate number of people aged under 50 by comparison with other types of cancer. According to Cancer Research UK statistics, an average of 27% of melanoma cases were diagnosed in people under the age of 50 incidence rises steadily from the age of 20. The average figure for all other cancer types (excluding non-melanoma skin cancers) combined was just 11%. But as with other cancer types, incidence of melanoma rises with age. According to 2010 data, the lifetime risk of developing melanoma in the UK is one in 55 for men and one in 56 for women.

Cancer Research UK figures also suggest that the majority of skin cancer cases are diagnosed at stage I and relatively few cases are diagnosed at stage IV. One- and five- year survival rates are very high for melanoma patients who are diagnosed at stage I or II, but much lower for those diagnosed at Stage III or IV. It is hoped that new treatments for advanced melanoma patients will increase these survival rates over time.

Recent Public Health England (PHE) figures presented to the Taskforce show that both incidence and mortality rates for melanoma have been increasing year-on-year in each nation of the UK. Melanoma incidence has changed significantly since the 1970s. Incidence rates for males have increased sevenfold, and have quadrupled amongst women, during that time. New PHE data shows that this rise also continued throughout the 1990s and 2000s. According to this data, three-year incidence rates for malignant melanoma in England rose considerably in both males

and females and in all nations of the UK since 1995. There has also been a similar increase in mortality rates over the same period, although this has been much more pronounced in men than in women.

However, there have also been a number of developments in treatment since 2010. Following the publication of the original Visions, three new therapies have been approved by NICE for advanced melanoma patients. The first two, ipilimumab (Yervoy) and vemurafenib (Zelboraf), were approved in 2012 and the third, dabrafenib (Tafinlar), followed in 2014. Much media attention has also been given to clinical trials for a number of new melanoma treatments. This has given further hope for increased survival rates and outcomes for patients with the most advanced form of the disease.

Non-melanoma skin cancers are also extremely common but cause relatively few deaths. There were more than 102,000 cases of non-melanoma skin cancer in the UK in 2011, the vast majority of which are basal cell carcinomas (74%) or squamous cell carcinomas (23%). The remaining non-melanoma skin cancers include a number of rarer skin cancers, such as Merkel cell carcinoma which can have a particularly poor prognosis for patients. There were 638 deaths from non-melanoma skin cancer in 2012. The majority of these were from either squamous cell carcinomas or basal cell carcinomas.



## EPIDEMIOLOGY

**Epidemiology is the study of how common a disease is and how it might be controlled. It is therefore crucial to understand the epidemiology of skin cancer before we can look at how to redesign services and improve patient care.**

The 2015 Skin Cancer Visions set an aspiration for the National Cancer Intelligence Network (NCIN) to work with practitioners to ensure universal compliance on measuring, recording, and reporting data to the skin cancer registry. While this aim has not been met, significant steps forward have been made by the NCIN and the benefits of this will be felt by skin cancer patients in future years. The NCIN went through a number of changes in the reorganisation created by the Health and Social Care Act 2012 and is now part of Public Health England (PHE). The National Cancer Registration Service (NCRS) is responsible for the registration of data relating to cancer, while the NCIN is responsible for its analysis.

As a result of this, the NCRS has become part of PHE's Disease Registry Directorate. In 2013, the NCIN launched the Cancer Outcomes and Services Dataset (COSD) which is the new national standard for reporting cancer data in the NHS in England. This will be the core dataset for all cancer types, but also contains stage-specific data for malignant melanoma. The South West Knowledge and Intelligence Team will also be moving its Melanoma Cancer Profiles for both Local Authorities and CCGs to the NCIN website in 2015. The NCIN has developed Hospital Trust-level Skin Cancer Service Profiles which will be published in June 2015 on the cancer commissioning toolkit.

This represents a considerable increase in the amount of epidemiological and registration data for skin cancer being collected in England.

However, there are still concerns that need to be addressed. This new data will take time to collect and analyse, meaning the benefits of having information at this level will not be immediately realised. Concerns have also been expressed about the consistency of data collection across the country. This is important to ensure the findings of any research are valid. It was also noted that there are a number of disparate datasets and that it would be useful to bring this data together in one place to truly capture the reality of skin cancer care "on the ground".

The Taskforce hopes that Public Health England will continue to collect as wide a variety of data on skin cancer as possible, with a particular focus on staging and outcomes. This data should be provided in a way that is both accessible and usable for patients, clinicians, commissioners and other policy makers. The work being done to develop service profiles and similar tools is a good first step towards this. The Taskforce strongly recommends that a similar level of data is also collected for non-melanoma skin cancers in order to properly assess the impact they are having on both patients and NHS services.



## IMPROVING OUTCOMES GUIDANCE

**Improving Outcomes Guidance is developed by NICE and offers suggestions for how care for particular conditions can be improved. NICE last produced skin cancer guidance in 2010. The Taskforce previously identified three key areas this guidance might focus on. These were:**

- **NHS Peer Review;**
- **Increasing the number of specialist staff working in skin cancer and ensuring care was organised in a multi-disciplinary fashion; and,**
- **Ensuring the introduction of a NICE Quality Standard for melanoma.**

Since 2010, progress against these objectives has been decidedly mixed.

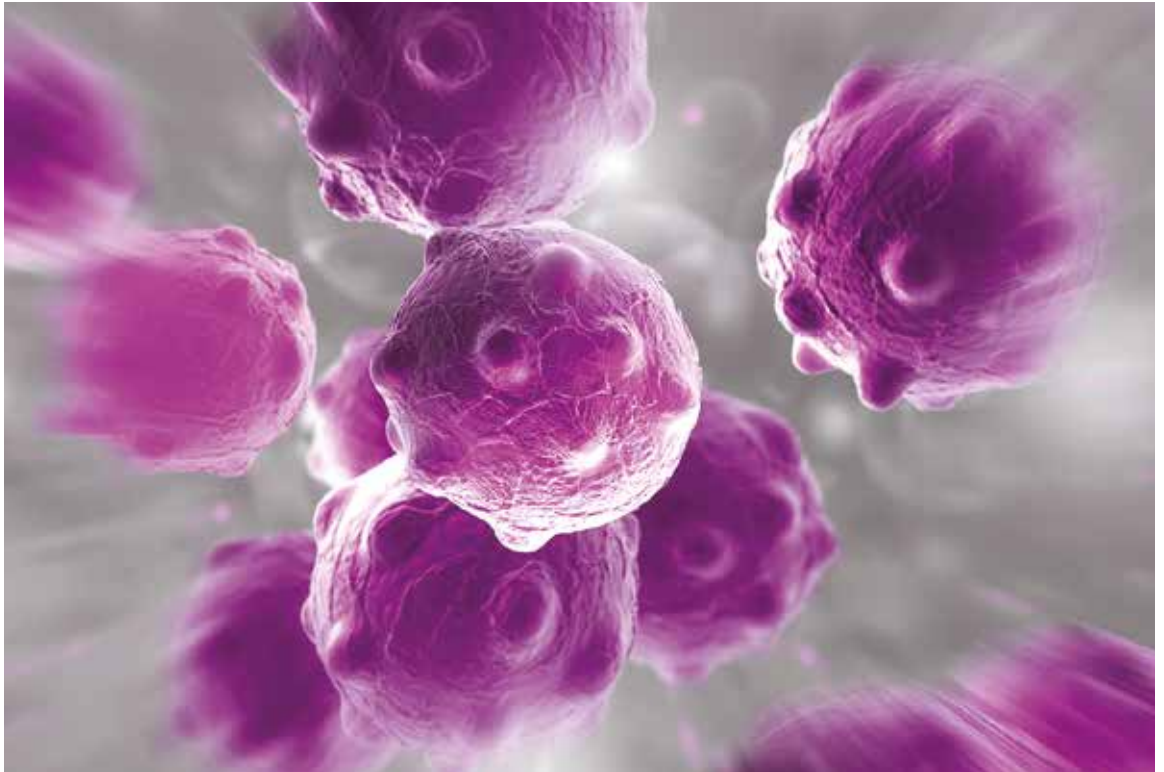
NHS Peer Review has been widely praised for its role in ensuring the quality of cancer services across different parts of the NHS. Its intention has been to externally assess the performance of individual Trusts and has been considered to be particularly useful for skin cancer. The skin-specific measurements used by Peer Review were last updated in the summer of 2014. Its last report on skin cancer, covering 2012/13, raised a number of “immediate risks and serious concerns”, including a lack of core multi-disciplinary team posts, pressure on clinical nurse specialists, a lack of funding for GP training and poor quality patient records.

The Taskforce has strongly supported the function performed by Peer Review but the future of the service looks uncertain. Peer Review now sits within NHS England and there continue to be doubts about whether funding is going to be available to continue the programme. If it is continued, it is unclear what form it will take. Taskforce members report that many Trusts are undertaking informal internal reviews, in lieu of the formal Peer Review process. While it is encouraging that Trusts remain keen to review their services on a regular basis, these processes may have to meet the same level of scrutiny as the national Peer Review programme and the resulting data will not be made available for comparison

between Trusts as has previously been the case. Without the scrutiny and recommendations for improvement provided by the Peer Review scheme, the quality of the care provided by Skin Cancer teams may stagnate over time.

One area of improvement since 2010 has been the development of multi-disciplinary teams (MDTs). These teams now usually include oncologists, surgeons and nurses, an approach that can lead to improved outcomes.

Despite this progress, there are increasing pressures on clinical nurse specialists and there is a shortage of specialist nurses currently working in skin cancer care. Similar fears have been raised about the number and availability of consultant doctors working in skin cancer. According to the British Association of Dermatologists, four out of five consultant posts remain unfilled. It has been suggested that many MDTs now list a nurse “with responsibility” for skin cancer as part of its membership, rather than a specific Clinical Nurse Specialist. This allows MDTs to claim a nurse as a member, and ensures that Teams have a nursing perspective when discussing patient care. But unless these MDTs include appropriate and qualified specialist staff patients will not receive the full benefit of a multi-disciplinary approach or the highest possible quality of specialist care. Many MDTs also do not include clinical psychologists amongst their membership, despite recognition of the value some patients place on being able to access psychological support. An expansion in the number of psychologists joining skin cancer MDTs in future and an increased availability of such care for patients to ensure the provision of a high level of aftercare following cancer treatment would be a welcome improvement.



Currently, skin cancer MDTs are based in secondary care. This means that primary care professionals are not included in the work of MDTs, despite their regular contact with patients. There are a number of GPs with a Special Interest in skin cancer or dermatology that could take on more responsibility for the diagnosis, triage and referral of patients with suspected skin cancers. NHS England should investigate whether this would be clinically and cost effective and if it would lead to improved patient outcomes. More GPs should also be offered training in dermatology and skin cancer awareness in order to improve their ability to deliver such services. Commissioners must also investigate whether it is possible to increase the number of those with Special Interest in this area and whether it is viable to include more primary care professionals within multi-disciplinary team meetings.

Some concerns have also been raised about the future of Site Specific cancer groups for conditions such as skin cancer. The future of strategic and site specific clinical networks, and particularly the future availability of the funding required to support them, is in doubt. Being able to share expertise across geographies is a useful way of building knowledge and ensuring examples of best practice are shared and implemented. It is essential that these teams have their future guaranteed and receive the funding they require to work effectively.

Finally, the Taskforce is keen to ensure that services and guidelines develop in a way that achieves the best possible outcomes for patients, both clinically and in terms of patient experience. Patients of all ages should be involved in discussions around the way services are designed and guidelines are developed. This will ensure that services are truly meeting the needs of patients as well as following clinical guidance recommended by NICE or NHS Peer Review.

## PREVENTION AND EARLY DIAGNOSIS

**With incidence rates rising, action to prevent the development of skin cancer is now more crucial than ever. The 2015 Visions called for a number of measures to be taken to improve prevention, including more joint working between the NHS, Public Health and skin cancer charities.**

The Visions also focused on ensuring that young people and schools played a leading role in raising awareness of the risks of skin cancer. Since the publication of the original Visions many positive steps have been taken. The Sunbeds (Regulation) Act came into effect in England and Wales in April 2011, helping to prevent people under the age of 18 from harmful sunbed use. Encouragingly, both the Welsh and Northern Ireland Assemblies have since gone further and passed additional regulations to ensure health information is available to adults using sunbeds, amongst other measures. This was a key recommendation in the original Skin Cancer Visions but there is undoubtedly more to be done to ensure that similar health information is made available in England and that appropriate training is given to staff working for sunbed providers across the UK.

The 2015 Visions also called for charities and public health officials to work together to target health prevention messages and to consider the viability of local pilot schemes to examine how best to deliver these messages. The Be Clear on Cancer campaign, now run jointly by NHS England and Public Health England in conjunction with charities and the Department of Health, has been running since January 2011 and aims to raise awareness of the signs and symptoms of a variety of cancer types. Bowel, lung, breast and ovarian cancer are among the tumour types covered by the campaign already and the campaigns have been associated with higher awareness of symptoms and increasing numbers of patients being referred. Based on this success, it was decided that a pilot scheme to assess the viability of a similar campaign for skin cancer should go ahead.



This pilot scheme was conducted in Devon, Cornwall and Somerset between 16 June and 27 July 2014 and included a mixture of press and radio adverts as well as targeted direct mail. The success of this campaign will now be evaluated by Public Health England which will then decide whether to expand it nationwide.





The Taskforce welcomes this pilot scheme and strongly supports its development as part of the nationwide Be Clear on Cancer scheme. A successful Be Clear campaign will raise awareness of the signs and symptoms of skin cancer and lead to more patients seeking advice from their GPs, being diagnosed and receiving treatment.

It is hoped that such a campaign would have the same sustained national impact as other Be Clear schemes, such as the campaign for lung cancer. While this focus on early diagnosis is important, the Taskforce would like to see an additional national skin cancer awareness campaign focusing on prevention and sun safety to help tackle the rise in skin cancer incidence. For this to be possible, it is essential that PHE and others work together to ensure that the messages contained within the campaign are targeted appropriately. It is also vital that a national campaign is adequately funded and is maintained over a sustained period to ensure that it has the maximum possible impact. The Taskforce believes that any campaign must have a lasting legacy and that a short lived and limited version will not have the impact needed to prevent the rising incidence of skin cancers in the UK. Awareness campaigns must also include messages aimed specifically at those groups for whom incidence is rising, such as those aged under 50 and people who work outdoors. One example of a campaign message that could be used in the UK is the “slip-slop-slap” campaign that was originally adopted in Australia in the 1980s and was associated with raised awareness of skin cancers.

One of the other major areas considered by the Taskforce in the 2015 Visions was the need to prevent skin cancers developing in young people. Much less progress has been made here. There are a wide variety of campaigns being run by patient groups and charities, who report difficulties with engaging with schools on this issue despite making materials easily available to them. The Department of Health, Public Health England and NHS England must encourage the Department for Education and Local Authorities to provide better information about sun safety and UV protection in schools. The example of Australia, where a great deal of emphasis is placed on encouraging children to believe sunblock is as essential as a bottle of water, is a good model for the UK to adopt. Concerns around vitamin D deficiency should

not be used to prevent skin cancer awareness campaigns from being aimed aimed at children and young people, although commissioners should also consider how best to ensure young people receive adequate vitamins while remaining ‘sun safe’.

The Taskforce has also developed guidelines which could be adapted by a variety of professions to encourage greater awareness. For example, the Taskforce and the British Association of Dermatologists developed Mole & Skin Check Guidelines for Health and Beauty Professionals in 2011. The NHS should make more use of these existing guidelines to ensure that work is not replicated and that advice on prevention and awareness can be disseminated as quickly as possible.



## SKIN CANCER AWARENESS AND PREVENTION CAMPAIGNS

Many different groups have taken on responsibility for delivering skin cancer awareness and prevention campaigns, aimed at a variety of audiences and using a variety of innovative methods. Some examples of these campaigns include:

### BRITISH ASSOCIATION OF DERMATOLOGISTS

**(BAD):** The BAD runs a number of Sun Awareness Campaigns, including a “Be Sun Aware” roadshow and the production of information leaflets and posters. The Association also organises the annual “Sun Awareness Week” each May.

Cancer Research UK: CRUK has run its SunSmart skin cancer prevention campaign since 2003. The campaign provides evidence-based information about skin cancer and sun safety to the public as well as working on policy development initiatives at a national level. In 2014, CRUK worked with Nivea sun on the Sun Has Got His Hat On campaign to encourage people to protect themselves from sun burn. It also worked with two fashion and beauty bloggers on The Ultimate No Make-up Selfie, giving advice on how tanning affects the skin and how to look good while avoiding UV damage. CRUK has also supported the national Be Clear on Cancer Campaign, which conducted its first skin cancer pilot in the summer of 2014.

### MYFANWY TOWNSEND MELANOMA

**RESEARCH FUND:** The Myfanwy Townsend Research Fund has also worked to raise awareness of sun safety in young people with its Outdoor Kids Sun Safety Code. The Code is a sun safety initiative and a free online resource bank aimed at young people doing outdoor activities outside of school and their coaches and teachers. The Code has been endorsed by a number of prominent sports people and governing bodies.

**SKCIN:** Skcin, formerly the Karen Clifford Skin Cancer Charity, has run a new and innovative campaign to raise awareness of skin cancer and sun safety in schools. The Sun Safe Schools campaign is an accredited scheme which aims to educate children about sun safety. The scheme includes sun safety advice provided to children, parents and teachers as well as lesson plans and interactive assemblies that encourage the children to become Sun Safety Superstars. The campaign is accompanied by George the Sun Safe Superstar, an illustrated story aimed at 3 to 10 year olds that helps to raise awareness of the Five S’s of Sun Safety.

**TEENAGE CANCER TRUST:** Teenage Cancer Trust runs an Education and Awareness Programme which provides education and advice about the signs of cancer, cancer treatment and prevention, healthy living and sun safety to 130,000 pupils across the UK each year. Young people also share the information they learn with their families meaning that this one intervention has a huge reach. The sun safety theme is currently being developed and expanded as part of this Programme. Stirling University carried out an independent evaluation of the Programme and found that the school talks increase the recognition of the number of cancer risk factors and warning signs and improves confidence to seek help when there are concerns.

Finally, the links between skin cancer and UV exposure have identified sun safety as a key driver in preventing the development of skin cancers. Suncream is therefore an essential way of protecting people at risk of skin cancer. Despite this, VAT is still charged on suncream – increasing the cost for those who need this vital form of protection. The Taskforce would encourage the exemption of suncream from VAT to ensure it is made available at a lower price to all.



## SCREENING

In the 2015 Visions, the Taskforce argued that there would not be enough data by 2015 to justify the development of a nationwide skin cancer screening programme. This remains the case and the Taskforce continues to believe that the NHS should focus on awareness and prevention measures rather than screening. At the same time, more can be done to improve the screening of at-risk groups.

Since the inception of the Taskforce, concerns have been raised across the skin cancer community that GPs and other primary care professionals are not receiving adequate training in dermatology and skin cancer. This is having a negative effect on diagnosis and treatment rates and ultimately on patient outcomes. This situation could be rectified in two ways. Firstly, primary care commissioners should encourage the greater uptake of tools such as the British Association of Dermatologists' GP Toolkit in order to provide up-to-date information and advice to practitioners. Secondly, GPs should be encouraged to take a greater interest in dermatology and skin cancer through the development of training and incentive schemes. The development of specific and mandatory continuous professional development (CPD) points for skin cancer and dermatology would be a welcome step towards the development of primary care expertise in these areas. Dermatology should also be a compulsory part of undergraduate medical training, as well as GP training, and should last for more than the current (optional) six days. The addition of incentive schemes for skin cancer and dermatology, such as QOF points, would also be welcome but increasingly tight budgets may mean this is not possible by 2020.



With greater training and awareness amongst GPs, they can then be utilised much more as a resource to screen at-risk patients and ensure that the signs of skin cancer are not missed. It is hoped that GPs will routinely ask patients in the most at-risk groups if they can check their skin during checkups for other conditions.

GPs will be better placed to inform patients about the signs and risk factors for skin cancer and encourage them to proactively inspect their own skin for suspicious moles and other symptoms. Ultimately, it is also hoped that increasing the level of training and awareness of the need for better dermatological care would create a greater number of GPs with a special interest in dermatology and skin cancer by 2020.

The lack of detailed and available data on skin cancers by stage is also a concern. While developments nationally are welcome, it may be possible for more information to be collected when patients are screened in both primary and secondary care. NHS England and the NCIN must investigate the viability of developing a national pro-forma data collection tool to be completed whenever a skin cancer is identified. This will help to develop nationwide information on the staging of these lesions. An online data collection tool has already been developed by

the NCRS and is available via the Royal College of Pathologists. This tool was launched in 2014 and its uptake should be encouraged.

It is acknowledged that sentinel node biopsy procedures may be helpful in correctly staging skin cancers and that such procedures may not currently be available to all patients. Commissioners should fund sentinel node biopsy procedures to ensure the same level of access to this procedure is available across the country, in order to ensure there is equity of access and that patients can access Sentinel Node Biopsy when it is judged to be clinically appropriate for them. Equally, new technologies, such as apps that can deliver images of suspicious moles from GP surgeries to secondary care to allow for faster analysis and referrals, should only be adopted for use if they are judged to be clinically effective using evidence-based analysis, such as a NICE technology appraisal.



## TREATMENT

**Since the 2015 Visions were published, the treatment landscape for melanoma has changed dramatically and a number of new treatment options are now available to patients.**

Three new drugs have been approved by the National Institute of Health and Care Excellence (NICE) since 2010: ipilimumab (Yervoy), vemurafenib (Zelboraf) and dabrafenib (Tafinlar). These treatments have the potential to radically improve survival rates for those patients with advanced melanoma. At the same time, one-year survival rates for patients diagnosed at stages I, II and III (which can usually be treated surgically) remain very high, with some data suggesting one-year survival for these patients can be upwards of 90%. In non-melanoma skin cancer, survival rates also continue to be high although these tumour types can have significant impacts on the lives of patients.

This is positive news for skin cancer patients but more can be done by 2020 to ensure patients are receiving the best possible treatment and care. In particular, a number of new treatment options are currently being developed and will be assessed by NICE over the coming years. It is essential that these treatments are also made available to patients in order to ensure they have the best chance of seeing long term survival and a better quality of life. The Taskforce is also concerned that the current funding situation in the NHS may mean that access to these treatments is becoming less, rather than more, likely. Any vision of the future of skin cancer services must include a wide range of effective treatment options if patients are to receive the best possible chance of surviving and living beyond their cancers. Industry, NHS England and NICE must do all it can to ensure new treatments are made available to patients as quickly as possible.

Surgery remains the best option to treat patients with early forms of skin cancer and this will undoubtedly still be the case in 2020. More must be done to increase the rates of patients being treated at an early stage. If adequate training can be provided to GPs by 2020, commissioners may wish to investigate the possibility of simple lesion removals being conducted within primary care settings. This should only be considered if it is judged to be clinically effective and specialists would still be expected to remove all melanomas. This would only be possible if all patient safety concerns could also be adequately addressed and there were appropriate pathology resources to audit suspicious lesions identified in this setting. The delivery of any skin cancer treatment, surgical or otherwise, will also require the availability of specialist staff. As well as funding better training for GPs and others to ensure they can play a greater role in skin cancer treatment, commissioners and medical schools need to do all they can to encourage oncologists and surgeons to consider skin cancer treatment as a speciality. This is crucial to ensure that new and existing treatment options are able to reach patients. Graduate surgeons should be encouraged to take part in local or specialist MDTs to develop experience in skin lesion excisions as part of their regular workload.

Between now and 2020, the development of new treatment options is also likely to mean that there will be a large number of clinical trials open to skin cancer patients in the UK. Anecdotal evidence suggests that both patients and clinicians have historically been keen to encourage patient entry into these trials to try to





achieve a maximised chance of survival. The Taskforce is keen to see this position maintained and expanded while these new treatments are developed, which will require two approaches to be taken. Firstly, the NHS and industry partners must maintain an atmosphere in which clinical trials are likely to take place in the UK. This means the NHS should do all it can to encourage trials to take place here and that clinicians must continue to be involved and to recommend patients for entry. More importantly, clinical trials themselves must be organised so that the greatest number of patients are able to take part. In particular, a greater range of trials should take place across the country in order to ensure there is little geographical disparity in where trials are available.

by expanding existing services for these patients. Young people with skin cancer, even if not treated at a specialist centre, should be notified to the age-specific MDT at Principle Treatment Centres for cancer in order to access specialist support. Any cancer diagnosis can be traumatic for patients and lesions on the skin, even when removed, can leave a lasting impact on patients and their self-image. Patients should receive the best possible aftercare, including the support of a clinical psychologist where a patient, their GP or oncologist considers it necessary or beneficial to improve their quality of life. This is currently a particular challenge for skin cancer patients, who often receive treatment as outpatients and are then forced to see a GP and receive a new referral before seeing a psychologist.



The new treatment landscape is positive news for patients but this greater hope of long term survival is accompanied by a new set of challenges for both patients and the NHS. In particular, the greater use of clinical psychologists in multi-disciplinary teams and a wider availability of such services must be encouraged. The relatively high incidence of melanoma in young people also comes with a unique set of psycho-social needs which must be addressed

This delays support being delivered to patients or may even mean that patients receive no support of this kind at all if they do not seek further help. By 2020, support of this nature must be routinely offered to patients and clinical psychologists should form a key part of a multi-disciplinary team for skin cancer.



Melanoma is recognised as a tumour type that may be particularly susceptible to a new form of cancer therapy known as “immuno-oncology” or “immunotherapy”. These treatments are currently undergoing clinical trials and are thought to work by stimulating the immune system to fight tumours for itself. Leading clinicians are, however, recognising that these drugs may have different side effect profiles and require different clinical considerations and protocols to be put in place in order to ensure patients are treated in a safe and effective way. One example is The Royal Marsden Hospital, which has played a leading role in clinical trials for this new type of treatment, and has experimented with the development of an “Immuno-Oncology Multidisciplinary team (IOMDT)” to consider their particular requirements and ramifications. Other organisations, such as Melanoma Focus, are working to actively encourage collaborations

nationwide. Immuno-oncology is playing a large part in discussions on future treatment options at Melanoma Focus meetings, which are attended by representatives from leading UK centres such as the Christie in Manchester, The Royal Marsden, Bristol, Leeds, Nottingham, Norfolk and Norwich, St George’s, The Royal London, Guy’s and St Thomas’ and Oxford. One example of a new collaboration arising from this work is the appointment of immunologists at King’s College Hospital to work with the skin cancer MDT at Guy’s and St Thomas’ Hospital. Trusts should consider introducing their own versions of these teams as these treatments become available and must also share best practice regarding how they are organised and operate. They should also consider appointing joint academic consultant posts across Trusts to encourage research and multi-disciplinary working in these new treatment fields.



**The Royal Marsden Hospital is piloting regular Immuno-oncology Multidisciplinary Team (IOMDT) meetings. The IOMDT is part of the Trust’s formal governance structure reporting into its main patient safety and risk management committee which also covers research governance. All clinical teams treating patients with immunotherapy are required to attend the IOMDT which meets regularly. The remit of the IOMDT meetings is education, research and governance with the aim of disseminating of best practice for the safe and effective administration of immunotherapy and developing optimal protocols for the management of immune-related side effects. The IOMDT meeting is also a forum for discussing new and ongoing research studies.**



**Dr James Larkin**  
Medical Oncologist,  
The Royal Marsden Hospital



However, there are also concerns about the future of cancer networks within the new NHS frameworks and particularly networks specifically focused on skin cancer. Local networks are now the responsibility of individual clinical commissioning groups and providers, who decide if they are required and how they should be funded. It is feared that this will mean many local cancer networks will disappear over the next few years, leading to a loss of forums to share experience and learning that many skin cancer clinicians value very highly.

The delivery of treatment is only one element of the patient pathway and adequate focus must also be given on the additional support patients require before, during and after their treatment. This is particularly true for patients with skin cancers that are at a more advanced stage. There are a number of patient support groups doing invaluable work in this area and it is vital that they can continue to do this between now and 2020.

## SUPPORT FOR ADVANCED PATIENTS

**There are a number of patient groups supporting those with advanced melanoma and other skin cancers, particularly at the end of life. Some of these services are listed below.**

**Macmillan Cancer Support:** Macmillan supports more than 900 independent cancer support groups and organisations across the UK. These groups can receive a wide range of support, including financial grants and resources as well as training for staff. The charity also runs a free support service by phone, which is currently available between 9AM and 8PM, Monday to Friday.

**Maggie's Centres:** Maggie's provide practical, emotional and social support to people with cancer and their families at Centres based within NHS cancer hospitals. The first centre was opened in Edinburgh in 1996 and there are now 17 centres across the UK as well as an online support service.

**Melanoma UK:** Originally known as Factor 50, Melanoma UK was founded in 2007 in memory of Jon Herron, an advanced melanoma patient. Melanoma UK provides support to melanoma patients and their families, as well as working with NICE to support appraisals of new melanoma treatments.

# 2020 SKIN CANCER VISIONS - A MANIFESTO FOR CHANGE

## EPIDEMIOLOGY

1. The new Cancer Outcomes and Services Dataset will collect a wide variety of data on all types of skin cancer, with particular focus on staging at diagnosis. The National Cancer Registration Service must ensure that an appropriate level of data is collected about non-melanoma skin cancers and that the focus of data collection is not wholly on melanoma.
2. The National Cancer Registration Service and its partners must ensure that the level and quality of data collected about skin cancers is consistent across Trusts and commissioning areas in order to ensure any analysis is reflective of the situation nationwide and that any variation is identified. It is also essential that the findings of this data collection and analysis are communicated to Trusts, commissioners and also other stakeholders such as patient groups.

The NCIN should also work with other organisations, from NHS bodies such as the Peer Review and service audits, to professional and patient groups, that hold data sets on skin cancer to ensure that the widest variety of available information is reported and collected centrally.

3. The NHS and Public Health England must support the NCIN to continue developing CCG, Local Authority and Trust-level Skin Cancer profiles to ensure they are maintained as a useful tool for commissioners, clinicians, patients and other partners across the skin cancer pathway. These tools must be regularly updated to reflect the most recent data from both the National Cancer Registration Service and the areas the profiles are reporting on.

## IMPROVING OUTCOMES GUIDANCE

4. NHS England must maintain the availability of Peer Review for cancer services and ensure that its role is properly funded over the course of the next Parliament and beyond. Peer Review must undertake regular external inspections of skin cancer services in England and the results of these reviews must be reported and analysed in a timely manner in order for issues to be identified and addressed and examples of high quality care disseminated and replicated as quickly as possible.
5. Peer Review must regularly update the skin cancer specific measurements it uses, in consultation with the skin cancer community and clinical experts, and must also undertake to publish a report on skin cancer services annually. NHS England must also respond to each report, outlining how it will address any “immediate risks and serious concerns” identified by Peer Review.
6. NHS England must work with all relevant bodies to encourage more trainee doctors and nurses to consider dermatology and skin cancer as a specialism. Furthermore, the amount of dermatology training available at medical schools must be increased in order to encourage healthcare professionals to recognise the signs of skin cancer, how to prevent their development and how they can be treated and patients cared for. NHS England must also do all it can to encourage the development of a larger number of Skin Cancer Specialist Nurses and GPs with a special interest in skin cancer.

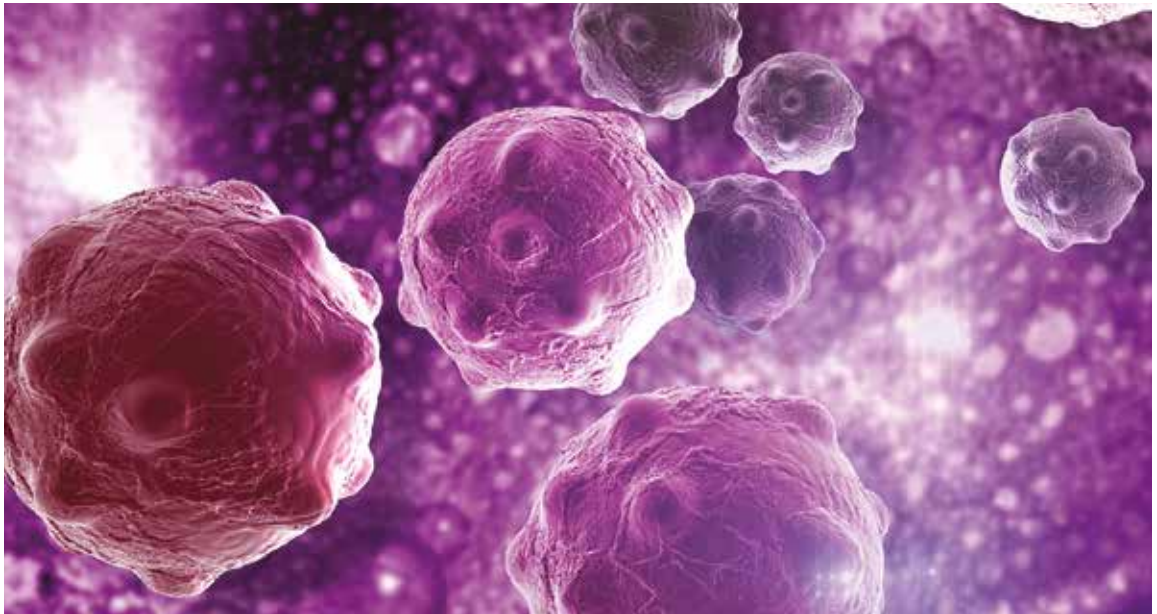


7. Commissioners of primary and secondary care must work together to develop a co-ordinated approach to skin cancer treatment in order to better involve primary care professionals, particularly GPs, in the work of Skin Cancer Multi-Disciplinary Teams. In particular, NHS England should explore ways of expanding the role played by GPs in treating certain skin cancers and the removal of skin lesions.
8. As well as including more GPs and primary care professionals in multi-disciplinary teams, it is essential that Trusts ensure that clinical psychologists are also included within their membership as standard in order to best reflect the psychological support needs of skin cancer patients. The NHS must do all it can to ensure there is adequate capacity within the workforce to make this viable.
9. The voice of patients is essential to ensure that any outcomes guidance is reflecting of the needs of those being cared for by multidisciplinary teams and other professionals. The development of any new guidance or procedures by either individual Trusts or at a national level must include consultation with patients and their representatives to ensure this voice is heard and fed into the development of new patient centred outcome measures.

## PREVENTION AND SCREENING

10. The Taskforce welcomes the decision to pilot a skin cancer awareness campaign as part of Be Clear on Cancer. The success of such campaigns should be regularly assessed and reported on, in as timely a manner as possible, in order to further refine the campaigns and make sure they are targeted at the right sections of the population.
11. The Department of Health should also commit to funding and supporting a national awareness and prevention campaign, alongside the Be Clear on Cancer campaign for skin cancer. Funding should be provided for this until at least 2020. This would ensure that the campaign has a significant legacy that will reduce the incidence of skin cancer and raise awareness of risk factors amongst the public.
12. The Government and Local Authorities must ensure that health information is available and provided at all sun bed outlets in England, as it is in Wales and Northern Ireland. Appropriate training on the health risks of sunbed use and the impact it can have on the development of skin cancer must also be provided to all staff in sun bed outlets in England and Wales, as it is in Northern Ireland. Such requirements should also be written into law at the earliest opportunity.
13. Skin cancers disproportionately affect young people by comparison to other cancer types and it is therefore hugely important that messages around awareness and prevention are delivered to people in this age group. One key way of doing so will be in schools and the Department of Health, NHS England and Public Health England must explore ways to work with both Local Authorities and the Department for Education to ensure skin cancer prevention is a key part of health elements in the national curriculum. This should include information on topics such as skin care, signs of skin cancer and the safe use and application of sun cream. More must also be done by Local Authorities and the Department for Education to ensure that campaigns run by patient groups and offered to schools are made available to teachers and pupils.





- 14.** Other at-risk groups should also receive targeted prevention and early diagnosis information. This might include groups such as outdoor workers and others with high exposure to the sun.
- 15.** Commissioners should also ensure that existing guidance on skin cancer prevention, such as that developed by the BAD, is disseminated to both primary and secondary care providers.
- 16.** The Taskforce continues to believe that a nationwide screening campaign is not viable and will not be by 2020, particularly considering continued budgetary pressures on the NHS. However, targeted screening programmes aimed at the most at-risk groups of patients may be viable over the same period and NHS England should investigate the possibility of the introduction of such a programme. NHS England should also continue to monitor evidence regarding screening programmes for skin cancer.
- 17.** New technology may also play a part in screening for skin cancer, including imaging apps that can assist with the diagnosis of suspicious moles. These should be adopted by commissioners where possible and if proven to be effective in order to speed screening and referral processes.
- 18.** NHS England should explore ways, including additional mandatory CPD points and QOF points, to incentivise GPs to learn more about skin cancers and to proactively screen patients for suspicious moles.
- 19.** NHS England should encourage the use of existing pro-forma for the recording of skin cancers during screening processes, with a particular focus on recording information related to stage at diagnosis to ensure data is collected in a uniform and wide ranging manner
- 20.** Sentinel node biopsy procedures should be funded at the same level around the country in order to ensure that patients and clinicians have access to this staging and diagnostic procedure if it is considered to be the most clinically effective option for a particular patient.
- 21.** The Treasury and the Department of Health should work together to make sunscreen VAT-exempt in order to reduce the price of this vital prevention measure and encourage wider use.



## TREATMENT

22. NICE should continue to look favourably on new treatment options for melanoma and should undertake to assess them for use on the NHS as soon as they are licensed and available in the UK.
23. NHS England should do all it can to encourage oncologists, dermatologists, nurses and surgeons to specialise in skin cancer treatment in order to ensure patients receive the highest quality treatment and care.
24. Support from clinical psychologists should be offered to all skin cancer patients following treatment. When patients are treated as outpatients, systems should be put in place to ensure that they can be referred to a clinical psychologist immediately, without being required to go to a GP to be referred first. As recommended above, the NHS should ensure that there is adequate workforce in place to deliver this.
25. Patients should have access to a clinical nurse specialist from the point of diagnosis in order to ensure appropriate advice and care is received across the treatment pathway.
26. Clinical trials, particularly those for new treatments in advanced melanoma, remain a hugely important resource for many patients. The NHS and central Government must ensure that it takes every available action to encourage such trials to continue to be based in the UK.
27. Clinical trial organisers, including pharmaceutical companies, must do more to ensure equitable access to clinical trials. In particular, action must be taken to ensure that trials are available across a broad geography. Additional support must also be given to patients to ensure they are able to access trials for which they are eligible.
28. NHS England and local commissioners should examine the possibility of introducing Immunology Multidisciplinary Teams (IOMDTs) to assist advanced melanoma patients who are being treated with new immuno-therapy drugs to manage their care and related side-effects.
29. NHS England should provide additional funding where necessary to ensure regional cancer networks, and particularly networks for skin cancer specifically, can be put in place.
30. The Department of Health and NHS England should do all they can to support patient support groups that are assisting patients with advanced skin cancers.





## CONCLUSIONS

**Since the publication of the original 2015 Skin Cancer Visions, the landscape for skin cancer patients has changed dramatically. The prospects of survival, particularly for patients with advanced melanoma, have improved considerably thanks to the availability of a number of new treatments that are remarkable advances on the traditional standards of care.**

The move towards multi-disciplinary working in cancer has also been of particular benefit to patients as surgeons, oncologists, nurses and others ensure they are cared for in a co-ordinated manner. The prospect of new awareness raising campaigns, including the Be Clear on Cancer campaign currently being piloting in skin cancer, is also positive news for the future. Sun beds have also been tightly regulated in some areas of the UK in order to help young people avoid increasing their risk of developing skin cancers. There are still issues with implementation and scope within this regulation that need to be addressed. The use of unmanned tanning salons, unregulated machine usage and lack of awareness of risk still poses a threat to the health of young people.

Despite these positive changes, there are a number of considerable challenges ahead. Statistics have shown that incidence of skin cancers continue to rise. This has been an ongoing trend across the UK since the 1970s. Meanwhile, changes within the NHS have put positive developments such as Peer Review on an uncertain footing and pressures remain on staffing levels and the availability of specialists. A perennial problem has been the lack of training for health professionals in dermatology and skin cancer and little action has been taken by the Department of Health or the NHS to rectify this situation since 2010. Perhaps most concerning, patient groups report that not enough has been done to raise awareness of the risk factors for skin cancer in order to prevent incidence from rising further. Patient group campaigns, particularly those targeted at schools, have not received the support needed to have the national cut-through required to have this impact.

The 2020 Skin Cancer Visions has laid out how the gains we have seen since 2010 can be maintained and how new challenges can be addressed. The 25 Visions set out specific recommendations for Trusts, Commissioners, NHS England and others to achieve by 2020 but several themes run throughout the whole report. In particular, it is clear to the Taskforce that more needs to be done to boost awareness and prevention measures for skin cancer. The introduction of a national Be Clear on Cancer campaign for skin will be essential in achieving higher rates of awareness of symptoms and early diagnosis. It is also hoped that primary care professionals, particularly GPs, can be used more widely across the skin cancer pathway. GPs could be more involved in skin cancer care beyond the first contact with the patient. Finally, with NICE making more treatments available for patients with advanced melanoma, it is key that commissioners start to look at issues relating to long term survival. It is hugely important that access to clinical psychologists as well as qualified skin cancer specialist nurses is available to patients, without exception, by 2020.

The Visions are the first step in a continuing journey to improved care for skin cancer patients. For reports such as this one to have an impact, stakeholders across the whole skin cancer community need to come together to ensure that these recommendations are implemented. The Taskforce looks forward to working with its members, with the NHS and the Department of Health and with Parliamentarians and Local Authorities to make these visions a reality.



# APPENDIX – WORKING GROUP MEMBERS



<b>Siân James MP</b>	Chair, Melanoma Taskforce
<b>Michelle Baker</b>	Myfanwy Townsend Melanoma Research Fund
<b>Jenny Geh</b>	Guy's, King's and St Thomas' NHS Foundation Trusts, BAPRAS & Melanoma Focus
<b>Anthony Hubbard</b>	Skcin
<b>Nellie Kumaralingham</b>	Clinical Nurse Specialist: Skin & Melanoma, UK Oncology Nursing Society
<b>James Larkin</b>	Consultant Medical Oncologist, The Royal Marsden NHS Foundation Trust
<b>John Major</b>	Campaigns Officer, British Association of Dermatologists
<b>Jane McCahy</b>	GPwSI, Kingston Clinical Commissioning Group
<b>Gill Nuttall</b>	Founder, Melanoma UK
<b>Veronique Poirier</b>	Knowledge and Intelligence Team South West, Public Health England
<b>Catherine Wheelhouse</b>	Chair, British Association of Skin Cancer Nurse Specialists
<b>Martin Whitehead</b>	National Oncology Policy Manager, Bristol-Myers Squibb



Introduction

Executive Summary & Priorities for Action

The Changing Skin Cancer Landscape

Skin Cancer in 2015 - where are we now?

2020 Skin Cancer Visions - a manifesto for change

Conclusions

Appendix – Working Group Members





The Melanoma  
Taskforce

# 2020 SKIN CANCER VISIONS

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